

People with aphasia, service providers and education working in partnership to provide long term support for people with aphasia

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Background Information

Long term language support for people with aphasia is a desirable but expensive health care option. Aphasia Leicester is a self help group that aims to supplement the local Speech and Language Therapy provision. Aphasia Leicester is an organisation where people with aphasia, the Leicestershire County and Rutland Community Health Services Speech and Language Therapy Department and De Montfort University provide ongoing support to people with aphasia at very little cost to both the service provider and the university. This co-ordinated and accessible approach addresses one of the recommendations of the National Stroke Strategy (2007 p42) as it provides a contribution to the long term care and support for people with aphasia. It also adheres to the Policy Statement for Stroke Survivors (2007 p12) produced by the Royal College of Speech and Language Therapists that suggests Speech and Language Therapy Services should work in close partnership with voluntary organisations. This model of partnership working between people with aphasia, service providers and educational establishments could be used in areas where currently no long term provision exists and no additional monies are available to start and maintain such an initiative.

History of Aphasia Leicester

Aphasia Leicester is based on another local self help group for people with aphasia, Aphasia Nottingham. This organisation, based in Nottingham for the last fifteen years, has provided an environment for people with aphasia to have conversations and gain mutual support. Rob Woodfield, a member of this group, moved to Leicester in 2004 and identified his need for the informal self help support system that he had received in Nottingham. In January 2005 Rob and Cressida Laywood, the chair of Aphasia Nottingham, approached the Leicestershire Speech and Language Therapy Department to discuss setting up a self help group for people with aphasia in Leicester. The Speech and Language Therapy Department welcomed this initiative and the first Aphasia Leicester coffee morning took place in the restaurant of a national retail outlet in April 2005.

Aphasia Leicester

People with aphasia are referred to Aphasia Leicester for support by the local Speech and Language Therapy department. This referral for voluntary organisation support is recommended by the National Clinical Guidelines for Stroke (2004 p53). Following referral the aphasia group facilitator, Rob Woodfield, sends a letter to the prospective new member inviting them to come to any of the Aphasia Leicester meetings.

Aphasia Leicester monthly activities	
First Wednesday of the month	Leicester coffee morning
Second Monday of the month	Oakham coffee morning
Third Monday of the month	Melton Mowbray coffee morning
Fourth Tuesday of the month	Market Harborough coffee morning
Fourth Wednesday of the month	DMU4 Conversation Group

Aphasia Leicester Coffee Mornings

At the coffee mornings people with aphasia and their relatives gather in town centre coffee shops in Leicestershire and Rutland. These meetings are organised by volunteer members like Rob. Leicestershire County and Rutland Community Speech and Language Therapists also attend the coffee mornings in Leicester and in Market Harborough. At these meetings people with aphasia have the opportunity to talk to others, practise their conversation skills and become more able to relax in communication situations. The groups also offer members the opportunity to socialise once a week. Conversations are usually centered around topical news stories. Special activities in addition to the coffee mornings have been organised including a Christmas meal and a narrow boat excursion.

DMU 4 conversation

The DMU4 conversation group provides a more structured and less distracting environment for members of Aphasia Leicester to practise and become more confident at communicating with others. DMU4 Conversation started in January 08. The University provide the accommodation and refreshments for the monthly, two hourly meetings. Attendance has been steady and the group has gradually attracted new members.

2008	Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov
PWA	7	9	12	9	9	9	9	12	12	12	14
Therapists	4	2	1	1	1	0	1	1	1	1	1
Students	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3	1
Total	11	11	13	10	10	9	10	13	13	16	16

2009	Jan	Feb	Mar	April	May	June	July
PWA	12	12	14	12	9	11	12
Therapists	1	1	1	1	1	1	1
Students	3	3	3	2	3	1	1
Total	16	16	18	15	13	13	14

From October 08 Speech and Language Therapy undergraduate students at De Montfort University have been given the opportunity to meet and talk to people with aphasia. This undergraduate learning opportunity occurs at the same time as the students are learning about the theory of aphasia therapy in their second year of the course. Within the meetings members participate in group discussions or talk individually to Speech and Language Therapy students. At the end of each meeting members decide upon a topic to talk about at the next meeting. Topics that have been discussed include: news stories, Christmas, the war, family trees and three things I would change if I ruled the world.

Evaluation

A focus group of DMU4 Conversation group members reported:

I like talking to people here because you're in the same boat
In society I find half the people don't understand what a stroke is
I had stroke two months not speak and I can talk but two months no I talk conversation yes
I think I'm reasonably well
Grandchild is fifteen let me know very well
I like to talk to people who've got aphasia as well cause you're out on your own in society
Talk to you
Make friendships
Had lost all confidence when I had this stroke

Carers have told us:

He's not quite so isolated
People are not just quite happy to walk in and ignore him here

Future developments

- Develop more links with national organisations such as Speakability and UK CONNECT
- Develop a more active marketing campaign
- Examine what attracts people to each of the groups and what other activities they might like to explore such as painting courses, wellbeing sessions and writing workshops
- Develop links with neighbouring self help groups

Future challenges

- Recruiting people with aphasia as coffee morning and group facilitators
- Retaining the goodwill and staffing resource of the local health authority and the university
- Integrating the different needs of the group members
- Measuring the impact of Aphasia Leicester

Conclusion

This model of partnership working between people with aphasia, service providers and educational establishments could be used in areas where currently no long term provision exists and no additional monies are available to start and maintain such an initiative.

References

Department of Health (2007) *National Stroke Strategy*. London: Department of Health.
Royal College of Physicians of London (2004) *National Clinical Guidelines for Stroke*. Second Edition. London: Royal College of Physicians of London.
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